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Patient and clinician reported outcomes for patients with new presentation of inflammatory arthritis: observations from the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis

Ledingham JM¹, Snowden N², Rivett A³, Galloway J⁴, Firth J², Z Ide³, MacPhie E⁵, Kandala N⁶, Dennison EM⁶, Rowe I³ on behalf of the BSR national audit Project Working Group

¹Rheumatology Department, Portsmouth Hospitals NHS Trust, Portsmouth, UNITED KINGDOM,

²Rheumatology Department, Pennine MSK Partnership, Oldham, UNITED KINGDOM,

³Clinical Affairs Department, British Society for Rheumatology, London, UNITED KINGDOM,

⁴Rheumatology Department, Kings College Hospital, London, UNITED KINGDOM

⁵Rheumatology Department, Lancashire Care NHS Foundation Trust, Preston, UNITED KINGDOM,

⁶MRC Lifecourse Epidemiology Unit, Southampton University, Southampton, UNITED KINGDOM.

Corresponding author

Dr JM Ledingham

Rheumatology Department

Queen Alexandra Hospital, Cosham,

Portsmouth,

PO6 3LY

E-mail: Jo.ledingham@porthosp.nhs.uk

Abstract

Objectives: A national audit assessing the impact and experience of early management of inflammatory arthritis by English and Welsh rheumatology units.

Methods: All individuals >16 years presenting to English and Welsh rheumatology services with suspected new onset inflammatory arthritis were included in the audit. Clinician and patient derived outcome and patient reported experience measures were collected.

Results: Data are presented for the 6,354 patients recruited from 1 February 2014 to 31 January 2015. 97% of English and Welsh trusts participated. At first specialist assessment DAS28 was calculated for 2659 (91%) of RA patients, mean DAS28 was 5.0 and mean RAID score was 5.6. After 3 months of specialist care mean DAS28 reduced to 3.5 and just over 60% achieved a meaningful DAS28 reduction. The average RAID score and reduction in RAID score was 3.6 and 2.4 respectively.

Of the working patients aged 16-65 years providing data 7%, 5%, 16% and 37% reported that they were unable to work, needed frequent time off work, occasionally and rarely needed time off work due to their arthritis respectively; only 42% reported being asked about their work. 78% of RA patients providing data agreed with the statement "overall in the last 3 months I have had a good experience of care for my arthritis"; less than 2% disagreed.

Conclusions: This audit demonstrates that most RA patients have severe disease at the time of presentation to rheumatology services and that a significant number continue to have high disease activity after 3 months of specialist care..

Objectives

In 2009, the UK National Audit Office (NAO) reported the cost effectiveness of early aggressive treatment of RA but also significant geographical variation in RA care across the UK [1]. The UK National Institute for Health and Care Excellence (NICE) 2009 clinical guidance (CG79) [2] and 2013 Quality Standards (QS33) [3] for the treatment of rheumatoid arthritis (RA) have emphasised the importance of early diagnosis and treatment of RA.

In February 2014, the British Society for Rheumatology (BSR), with its information technology (IT) partner Northgate Public Services launched a Healthcare Quality Improvement Partnership (HQIP) funded national clinical audit of the management of early inflammatory arthritis (EIA).

The audit aims to assess the early management of patients referred to English and Welsh rheumatology units with suspected inflammatory arthritis and to enable patients to provide feedback on the services provided to them and on the impact of their arthritis on their daily lives. The ability to work has been demonstrated to be highly important to individual's health and welfare and to the wider economy so this was also assessed within this audit [4]. The audit enables rheumatology services to measure their performance, patient outcomes and experience, benchmarked to regional and national comparators for the first time.

Methods

The data collection tools were developed by the audit project working group and approved for use by HQIP and the NHS Review of Central Returns (ROCR), now renamed the Burden Advice and Assessment Service. There was a pilot of the questionnaires and web-based information technology (IT) tool prior to the audit launch in February 2014. Patient consent, using HQIP and ROCR approved processes, was obtained at baseline and recorded for all analysed data.

All individuals > 16 years presenting to specialist rheumatology services in England and Wales with new onset peripheral joint polyarthritis were included in the audit. Patients were recruited if they had RA, psoriatic arthritis, peripheral arthritis linked with spondyloarthropathy (not pure axial spondyloarthropathy) and undifferentiated arthritis but were excluded if they had crystal arthritis or arthritis caused by infection (viral or septic arthritis) or linked with connective tissue disorders/vasculitis.

Clinician derived 28 joint disease activity scores (DAS 28) [5] were recorded, when assessed at appointments, at baseline and up to 3 months of specialist review for patients with an RA pattern of disease (defined by the presence of polyarticular disease (>5 joints involved) or pauciarticular disease with positive CCP antibodies). Follow up data capture was for Rheumatoid Arthritis (RA) patients only, given the quality standards being assessed are for RA

Patient reported outcome and experience measures (PROMs and PREMs) and information on ability to work were also collected.

The PROM used was the Rheumatoid Arthritis Impact of Disease (RAID) score [6]; a validated tool for RA patients. The RAID score is a patient-derived composite measure of the impact of RA, assessing pain, functional capacity, fatigue, physical and emotional wellbeing, quality of sleep and coping. The overall score ranges from 0 (best) to 10 (worst). PROM data was collected for all patients at presentation and after 3 months of specialist review for RA patients. Prior to this audit's launch, there were no established tools for assessing work status in patients with inflammatory arthritis. Following consultation with experts in the field and with patient representatives, a short questionnaire was developed, agreed and piloted and was completed as part of the patient follow up questionnaire. Impact on a patient's ability to work is presented for patients of working age i.e. 16-65 years.

The PREM used was an adaptation for use at 3 months of the tool developed by Commissioning for Quality in Rheumatoid Arthritis (CQRA) group with the UK National Rheumatoid Arthritis Society for patients with RA [7]. To ensure confidential feedback PREM data was collected after 3 months of specialist review via individuals not involved in the patients care. The processes adopted were necessarily individual to individual trusts but, in general, were provided by non clinical audit staff. The

PREM question analysed for this report was “overall in the past 3 months I have had a good experience of care for my arthritis” with responses categorised as agree (agree or strongly agree), neither agree nor disagree, disagree (disagree or strongly disagree) and not answered. Individual trusts have access to the full questionnaire responses. Translators required for any consultations were available to assist patients with their questionnaires.

Achievement of the 7 NICE Quality Standards [3] and information on key factors potentially impacting on patient experience and outcomes (catchment population; numbers of whole time equivalent consultants and specialist staff; availability of EIA clinics) were also assessed and are reported separately [8].

The Medical Research Council (MRC) Lifecourse Epidemiology Unit in Southampton analysed the data.

Results

Data are presented for patients recruited from 1 February 2014 to 31 January 2015. 143 of 148 eligible National Health Service (NHS) rheumatology providers in England and Wales registered to participate in the audit and 94% of these supplied data. Data from 6,354 patients were analysed, representing > 40% of expected incident RA cases.

Details of the patient demographics, diagnoses and on departmental staffing levels per head of population are within a further submitted paper[7]. Patients were predominantly women (66%) and 70% were of working age (aged 16-65 years). The majority of patients recruited were of white British origin (79%) but there was significant geographical variation in ethnicity. Forty-six percent (55% of patients with a confirmed diagnosis) had RA diagnosed at baseline.

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DAS 28 Data

Nationally, at the point of first specialist assessment, DAS 28 was calculated for the vast majority of RA patients (91%, 2659); when assessed within NHS regions and within Wales, DAS 28 was available for 99% of RA patients in Wales but for only 85% in the South of England. Mean DAS 28, the proportion of RA patients with high (>5.1), intermediate (3.2-5.1), low (<3.2) DAS 28 and with missing DAS 28 at baseline nationally and by NHS region is shown in table 1. The mean baseline DAS 28 was 5.0 with little regional variation (4.9 in the Midlands and East of England – 5.1 in the South of England and in Wales). Approximately half (45%) of patients had severe disease at presentation; Wales and the Midlands and East of England reported the highest (51%) and lowest (43%) proportion of patients with severe disease activity respectively.

Table 2 show these data derived after 3 months of specialist care together with the proportion of RA patients in remission (DAS 28 <2.6) and achieving a meaningful reduction in DAS 28 [9]. Nationally the proportion of missing data at follow up increased to 28% (23% in London and the North of England and 39% in Wales). The mean DAS28 for RA patients had reduced to 3.5 for all regions. 24% of RA patients at follow up were in remission (26% in Wales, 22% in the South of England and Midlands and East of England regions) but 11% still had high disease activity (14% in London, 8% in Wales). Nationally just over 60% of RA patients with available baseline and follow up DAS 28 achieved a meaningful reduction in DAS 28 of >1.2; the highest and lowest achievement rates were observed in Wales and the North of England (67%) and the Midlands and East of England (57%) respectively.

RAID data

Table 3 summarises the national and NHS regional data for RAID scores supplied by all EIA patients at baseline and for those with RA at follow up. RAID scores indicated generally severe disease activity at the point of diagnosis with an EIA within rheumatology units; the mean score was 5.6 nationally with a range of 5.5 (South of England) to 5.8 (Wales and the North of England).

RAID data at follow up were available for 25% of patients with a confirmed RA pattern of disease. The national average RAID score at follow up was 3.6 with a wider range of scores (mean 3.1 in the North of England to 4.2 in Wales) supplied by patients at follow up than at baseline. The average reduction in RAID score nationally was 2.4 with the North of England achieving the highest (3.9) and Wales achieving the lowest (1.7) reductions in scores. At three months, these mean reductions fall short of the validated minimum clinically important difference for RAID (defined as a reduction of 3 points or more or a percentage reduction of 50% from the baseline score) [10].

Work data

Tables 4 and 5 summarise the data received from patients on their ability to work and on whether they recalled being asked about their work. Again very few patients (748) provided data and there was variation in data across the NHS regions. 26% of the patients aged 16-65 years that returned their patient questionnaires reported that they were not working but this was not because of their arthritis or that they were undertaking voluntary work. Of the remaining patients of working age that provided data:

- 7% reported that they were unable to work due to their arthritis.
- 5% reported that they needed frequent time off work.
- 16% and 37% respectively reported that they occasionally and rarely needed time off work.
- 42% reported that they had been asked about their work (49% in the South of England and in the Midlands and East of England; 30% in London)

PREM data

Table 6 summarises the PREM data received nationally and for NHS regions. As for the RAID and work data only a small number of RA patients (577) completed their questionnaires after 3 months of follow up; even when these questionnaires were returned the PREM question was not answered by 17% of patients. Nationally 78% of RA patients providing data agreed with the statement “overall in the last 3 months I have had a good experience of care for my arthritis” (87% in London and 76% in the South of England) and less than 2% disagreed or strongly disagreed.

The national and NHS regional findings summarised above disguise considerable variation at individual trust level.

Discussion

This HQIP funded audit has allowed the first comprehensive national benchmarking of care given to people with newly diagnosed inflammatory arthritis for England and Wales.

The population of patients recruited and the spread of confirmed diagnoses at first appointment were largely as anticipated, with the majority of patients with a confirmed diagnosis at recruitment having RA.

As reported in the other linked paper [8] data quality was generally good. Data were collected from the vast majority of trusts but some trusts were unable to recruit anticipated numbers of patients. Missing data was a particular problem however for patient derived data and for some of the clinician derived follow up data and this should be borne in mind when interpreting the results.

There were missing data for DAS 28 in only 9% of RA patients nationally at baseline indicating that the vast majority of clinicians are now calculating a DAS 28 for patients seen with RA within the context of the audit. Wales reported DAS 28 assessment for virtually all patients but rates were much lower in the South of England (85%). The variations in DAS 28 reporting may reflect variation in practice but could also be a reflection of data quality with higher levels of missing data in the South of England. Whilst regular assessment of disease activity including DAS 28 is considered good clinical practice it only becomes mandatory in the UK when patients need to be assessed for biologic therapy

later in the disease course. To be eligible for biologics in the UK patients are required to have at least two DAS 28 of >5.1 , assessed at least a month apart, despite use of at least two conventional DMARDs for at least 6 months.

Nationally, and for each region, the highest proportion of RA patients with DAS 28 data available had severe or moderate disease activity at presentation (84% nationally).

Patient derived disease activity measures were available for most EIA patients at baseline. Although RAID is a validated tool for RA it assesses domains relevant to all inflammatory arthritis problems and was collected at baseline to ensure that scores were available for all patients that were later established with a diagnosis of RA. As with the clinician derived assessment (DAS 28) the RAID indicated a generally severe level of disease at the point of presentation to secondary care. Ideally systems need to be implemented to help identify patients with EIA and allow them to be seen within specialist services before their disease has reached severe levels. There was no evidence for significant geographical variation in disease severity at the point of first specialist review but clinicians and patients in Wales reported the highest DAS 28 and RAID scores at baseline. The overall range of scores however was very wide indicating that, whilst the majority of patients presented with moderately severe disease, there were patients presenting with very mild but also with very severe disease.

Missing data for DAS 28 at follow up hinders interpretation of the results. The available data show that nearly two thirds of patients achieved a meaningful reduction in DAS 28 and a quarter achieve remission after 3 months of specialist care and this suggests that treatments initiated for patients with RA are having impact in this relatively short time frame of specialist care for most patients. These results however also show that 11% of patients nationally still have severe disease activity after 3 months of specialist care and this highlights scope for further improvement in the early management of RA in our patient population.

A second RAID score was requested from all RA patients after 3 months of specialist care but baseline and follow up data were only available for 509 patients so again this limits interpretation of the results. Interestingly although average DAS 28 was the same across all NHS regions after 3 months of follow up there was variation in the average RAID scores from 3.1 – 4.2. In addition, at population level, greater improvements in DAS 28 were not mirrored by similar improvements in RAID. For example Wales achieved a meaningful reduction in DAS 28 in the highest proportion of patients but also the lowest mean reduction in RAID score. The RAID score covers more holistic aspects of the impact of disease on an individual, including emotional well-being and coping than the DAS 28 and this may, in part explain this discrepancy. Further research into factors influencing response to treatment as recorded by DAS 28 and by RAID could improve our understanding of this particular result.

The lack of a meaningfully clinically important reduction in RAID score for the majority of patients is disappointing and indicates scope for improvement in managing patient's symptoms and coping strategies in the early stages of their disease. This maps to the failure of the majority of patients to achieve a previously set treatment target [8] and is important. An explanation for this may partly lie in the short follow up duration of the audit (acknowledging DMARD therapy often takes more than 3 months to achieve full effect) and with issues around capacity to provide intensive review and treatment escalation. However, a further consideration is that RA has a serious impact upon function and performance, which may persist despite apparent control of the inflammatory burden (reflected in good DAS control). This observation highlights the need for rheumatologists to use tools beyond simply the DAS 28, or other objective measures of inflammation such as joint ultrasound, when measuring treatment response. Indeed, measures of pain, fatigue and physical function are perhaps the most relevant outcomes for patients, despite being poorly captured in routine care.

The impact of specific treatments (steroids, DMARDs), on DAS 28 and RAID score has not been assessed as part of this audit but would be an important areas for future research. Whether patient education and support for self management influences components of the RAID score is also worthy of exploration.

Early arthritis most often presents in people of working age [11]. Over 70% of people recruited to this national audit were under 66 years of age. There is overwhelming evidence that established

inflammatory arthritis has severe and often permanent effects on work capacity although there is some evidence that work retention is improving [12]. Health and social care interventions designed to keep people in work are therefore a crucial part of the effective management of inflammatory arthritis. Our data on work related outcomes are limited because so many participants did not answer the work related questions. However the existing data suggest that impact of work capability is small in the very early stages of EIA. This suggests that early disease may be a crucial time for work-related interventions, before work instability translates into long term work incapacity. The relationship between changing work status, demographic factors and clinical parameters would be of interest and worthy of future research.

As emphasised by Dame Professor Carol Black, interventions around work will not happen unless questions about work are part of the clinical consultation [13]. Previous data suggest that providers of rheumatology services believe that those questions are asked [], but evidence from the National Rheumatoid Arthritis Society [14] suggests that the majority of patients do not recall being asked about work. Data from this National Audit echo the findings from the National Rheumatoid Arthritis Society, with only 42% of patients returning the work related questionnaire recalling being asked about work. Patient recall may be contributing to these statistics but these data suggest an aspect of care that can readily be improved and may in themselves act as a spur for including work issues in the clinical consultation. In support of this important component of patient care the BSR is working with Cardiff University to implement a regional training programme across the UK to encourage clinicians to discuss work issues within consultations.

In the absence of a validated composite score for the PREM, the responses to the overarching question 'overall in the past 3 months I have had a good experience of care for my arthritis' has been reported. The low proportion of RA patients completing their PREM questionnaires after 3 months of follow up again limits the ability to draw any substantial conclusions from the data supplied. The low data return rate is disappointing as the PREM is an important source of information on how trusts are meeting the needs of their patients. The low rate of data supply may relate to complexities linked with data collection processes. In order to protect patient confidentiality and encourage honest feedback completed paper questionnaires had to be returned to individuals not directly involved in the patient's clinical care and then uploaded to the database. These confidential processes may have impaired data capture.

Nearly one fifth of RA patients failed to supply a response to the question analysed for this report when returning the PREM questionnaire and the reasons for this are unclear. The PREM questionnaire was originally developed and tested for use after 12 months of specialist care and was modified for use at 3 months for this audit. It is possible that patients did not feel able to provide the reasonably detailed feedback on their experiences after just 3 months of care. At the time of finalising the audit questionnaires, there were no alternative validated PREMs.

The PREM data that are available are broadly re-assuring, however trusts are encouraged not to be complacent in interpreting these results. Of some reassurance only a small proportion of RA patients (1% nationally) reported that they disagreed or strongly disagreed with the PREM question on overall quality of care. Trusts receiving such feedback are, in particular, encouraged to examine the full detail of the PREM data, to explore mechanisms for gaining further feedback from patients and to review aspects of service provision that may impact upon patient experience.

Overall this national audit has provided clinicians with feedback on clinician and patient reported outcomes, including information on ability to work, for their patients with RA and this is the first time such data has been available with national and regional benchmarking. In addition some limited feedback on patient experience of rheumatology specialist services has been obtained. This audit has highlighted the difficulties in obtaining data within busy clinic settings and in particular highlights the difficulties in obtaining important patient derived information in such settings.

The audit has revealed a clear need for the NHS to develop better systems for capturing, coding and integrating information from outpatient clinics, including measures of patient experience and outcome and measures of ability to work.

This audit is on-going and further research using the data collected should help improve our understanding of the factors that influence outcome for patients with an EIA and RA.

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Declarations of Interest

All authors have submitted declarations of interest. JL has no personal declarations but her department receives support from Actelion for blood testing kits for pulmonary hypertension, from UCB for TNF drug level testing kits and from Abbvie for clinical practice events, ultrasound training and a patient DAS app pilot,. JG has received honoraria from Pfizer for educational talks and holds an i-CRP grant.

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